Tool to Estimate Patients' costs

Literature Review / Discussion paper

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1.1. Conceptual Framework

Tuberculosis is a disease that disproportionately affects the poor. TB programs therefore need to ensure that the economically and socially disadvantaged groups do not face barriers that keep them from seeking treatment. In addition, TB programs need to ensure that TB doesn't stand at the beginning of a spiral into poverty. The question therefore is how a TB program can target the poor and alleviate their financial burden.

The WHO guideline *Addressing Poverty in TB Control* (2005) lists four different kinds of barriers to access care: geographical, social/cultural, health system and economic barriers. The three main types of costs are: 1) charges for health services, 2) transport, accommodation and subsistence and 3) lost income, productivity and time.[1] Individuals suffering from TB are often in their economically most productive age, which poses a significant economic burden on the household. Poor people have longer pathways to care and costs of accessing care are generally higher before than after diagnosis.[2] Relative costs for poor people as a percentage of their income is much higher than for non-poor patients, although aggregate real costs may be smaller.[3] Out-of-pocket costs for public and private health-care services may stand at the beginning of a spiral into poverty for many families and exacerbate the poverty of the already-poor. This situation has been termed the "the medical poverty trap"[4]. Stratification of patients along several indicators (gender, geography, socioeconomic status) is therefore necessary.

By addressing barriers and reasons for delay to timely diagnosis and treatment by the NTP, costs to TB patients, particularly among the poor, can be effectively reduced. The Poverty Sub-Working Group of the Stop TB Partnership has therefore decided to develop a tool which can assist TB programs to estimate the costs of TB patients before and during diagnosis and during treatment by the NTP. The tool to assess patients costs will make economic constraints to individuals and households more apparent. With the help of more adequate information on patient costs, it will be easier to design targeted, alleviating measures.

The tool should

- be a feasible and realistic tool,
- be applicable world-wide
- permit national programs to estimate the costs for TB patients before & during diagnosis and during treatment
- relate to all sectors providing TB care
- consider costs due to HIV-Co-infection

<u>The aims of the tool are:</u>

- To make economic constraints to individuals and households more apparent.
- To provide means to assess the impoverishing impact of TB on patients and their families.
- To establish an evidence-base upon which subsequent interventions can contribute to poverty reduction, increased equity in access to diagnosis and treatment, increased case detection, better treatment adherence

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[1] WHO 2005
[2] Nhlema et al 2003, Kamolratanakul 1999, Rajeswari et al 1999
[3] Nhlema et al 2003, Kemp et al 2007
[4] Dahlgren & Whithead 2006

Objective of the literature review

As a first step to develop the tool, a literature review on studies dealing with patients costs and methodologies employed has been conducted. The objective of this review is to provide a detailed account of research findings at which stage what kinds of costs are incurred. The findings of the review will form the basis and context upon which the tool will be developed.

Literature was identified through searches of meta-databases such as PubMed/Medline, EBSCO host, Elsevier, Science Direct and to a large extent through examining bibliographies and references of published material. Publications in English, French and German, with a special focus on publications since 1990 were sought.[5] Inclusion criteria were applied to identify studies that had dealt with low or middle-income countries or with methodologies employed to measure cost of illness (including studies not dealing with TB). Studies exclusively dealing with costs to healthcare providers were excluded. Studies were screened for methods employed, stage of diagnostic/treatment process when costs were assessed and findings related to delays and indirect and direct costs for patients or households. This yielded a total number of 29 studies. In addition, three studies that only deal with patient delays were included for comparison of delay times. The studies cover the following countries:

Africa: Malawi, Zambia, Sierra Leone, Ghana, South Africa, Ethiopia, Tanzania, Gambia, Uganda

Asia: India, Thailand, Myanmar, Bangladesh, Viet Nam, China

Latin America: Haiti, Bolivia

Europe: --

1.2. Definitions

Studies on the cost of illness to patients or households aim to get a comprehensive idea of illness costs incurred by patients. Illness costs are broken down into direct and indirect costs. Direct costs are out-of-pocket costs linked to seeking diagnosis and treatment including medical expenses, fees, transport, accommodation and food expenditures. Indirect (opportunity) costs differ from financial cost as they include the cost of foregone income due to the inability to work because of the illness and loss of time due to visits to health facilities, time spent on the road to and at health facilities, lost productivity and loss of job. Another approach used by the Commission on Macroeconomics and Health (2001) includes the translation of loss of well-being of a patient into economic cost. This can be subdivided into three parts a) the reduction in market income due to the disease, b) the reduction in longevity, c) the reduction in psychological well-being (pain and suffering).

Besides direct and indirect costs, a third category of costs are those incurred through coping strategies (coping costs) of a household to meet daily requirements despite extra expenditures or loss of income. These include the sale of assets, taking up debt, saving on food or other items, taking a child out of school to care for the patient or taking up another job (Russell 2004).

The economic unit is either the individual or the household. Since direct and indirect illness costs fall on the caregiver and the patient, the household is generally the preferred unit of analysis, but

[5] Search keywords included TB + patient cost, household cost, cost diagnosis, spending, treatment cost, affordability, cost, cost-effectiveness,TB-HIV, Coinfection, HIV, DTC, VTC, cost evaluation, expenditure, socioeconomic, care barriers, treatment affordability, financial costs, economic costs, economic burden, economic impact, access to treatment, economic evaluation, methods cost evaluation, healthcare costs.

data is often collected on a per capita level. This review subdivides costs incurred into the stages where they occur:

1) Before Diagnosis
2) During Diagnosis / Pre-Treatment
3) During Treatment

The causal linkages of these factors are depicted by Russell (2004), p.148:

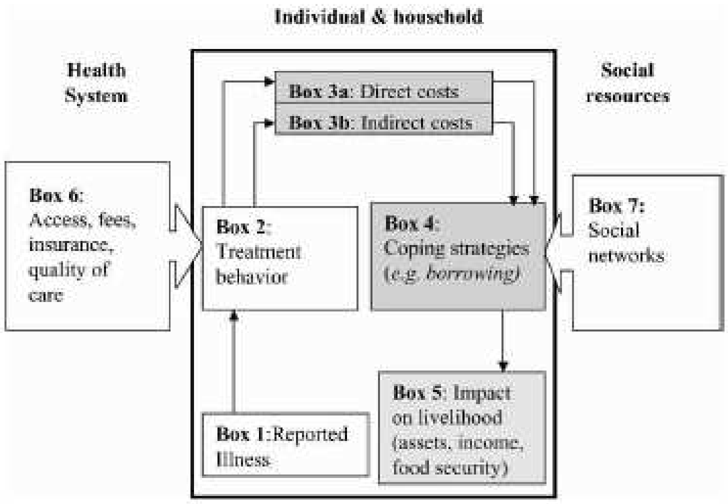

FIGURE 1. Conceptual framework for analyzing the economic burden of illness for households.

At the stage of boxes 1 and 2, decisions are made whether and how treatment is sought as a response to the event of illness. The health system is captured in Box 6. Direct costs capture expenditures related to seeking treatment while indirect costs are loss of labor time for patients and their caregivers. The severity of illness and characteristics of health services affect direct and indirect costs and influence access to and choice of provider. The cost burden and coping strategies of struggling with this burden (mobilizing resources outside the household such as credit – box 7) determine household assets and impoverishing processes, hence the link between illness and poverty.[6]

1.3. Approaches to measure the cost of illness (Malaney 2003)

There are four approaches to measure the cost of illness: The Human Capital Method, the Willingness to Pay model, the Production Function approach and the Friction Cost method. The first two are the classic ones deriving from the 1960s. All of them but the last assess the cost of illness to an individual as well as to society. The following summary will focus specifically on the aspects related to patients cost and neglect some of the aspects mentioned in the literature regarding macroeconomic measurements of the cost to society.

The **Human Capital Method** (HCM) estimates the cost to society of lost future productivity, discounted to the present. The calculations aim at a sum of future earnings of the premature

[6] Russell 2004

dead by looking at life expectancy, labor force participation and average salary data. This is sometimes called the ‘top-down-approach’. It includes direct and indirect costs. Indirect costs are productivity losses, measured by estimating income foregone due to morbidity and mortality. The cost of morbidity is the value of lost workdays. Future earnings are discounted to assess the present value of lost income. (One dollar in a year from now is worth less, than a dollar today, taking into account the cost of capital during this year.) Calculations should include lost value of unpaid work in the household, but it is almost never done, due to its difficulty of assessment. The same holds true for the assessment of pain and suffering.

The standard formula for the total costs of illness is:
Cost of illness = private medical costs + non-private medical costs[7] + forgone income + pain and suffering

The HCM has been criticized of inaccuracy when assessing productivity: where productivity is lost, labor substitution by other family or community members happens. Labor then falls disproportionately on women. Second, it does not incorporate forgone household activity and leisure time. In addition, the use of wages as measure of productivity is criticized. Hence, the HCM approach, though used widely, struggles with capturing costs that are not easily measurable in numeric terms.

The **Willingness To Pay Method** (WTP) deduces (by means of household surveys or revealed preferences) the monetary value that a person associates to variations in risk of illness (or death). It is therefore sometimes called the bottom-up approach. It incorporates the cost of pain and suffering, since people are expected to include them when evaluating how much they would pay to reduce their risk of illness or death. Malaney (2003) notes that the cost of an illness on welfare of the household can be determined by the value the household would put on avoiding the disease. This would capture lost productivity, treatment costs, forgone leisure time and pain and suffering.
It has been argued[8] that, in comparison with WTP, the HCM understimates the economic burden of disease on households.

Ability vs. Willingness to Pay
According to Russell (1996), costs of accessing healthcare are affordable, when service utilization is not deterred for financial reasons and opportunity costs don’t cause levels of consumption and investment go below minimum needs in the short run. Fabricant et al (1999) considers expenditures as affordable if they have no lasting effects on health, economic or social status on the household. There seems to be consensus though that 3-5% of annual income spent on healthcare expenditures are affordable.[9] Russell (1996) argues that willingness to pay is not equal to ability to pay for the poor, because they might be willing but unable and therefore compensating by sacrificing on nutrition and other important items. Jack (2000) describes the decision of the individual to seek diagnosis to be based on the weighting of the benefit of early detection with the cost. The weighting changes with the severity of symptoms. When the symptoms are bad enough for the expected benefit of diagnosis to outweigh the cost, medical attention will be sought. Reducing the costs of seeking care will help to induce individuals to seek care early. Willingness to pay for treatment is therefore correlated with income and costs of treatment with availability of services.

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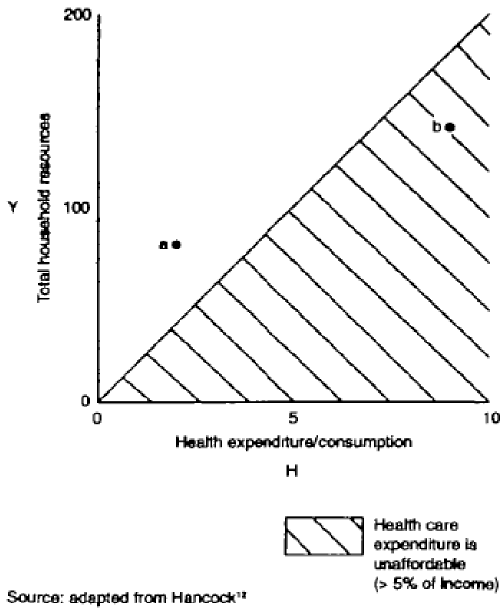
[7] “Non-private medical care costs are public expenditures on both prevention and treatment of the disease” (Malaney 2003, 5)
[8] Malaney 2003
[9] Russell 1996, Russell 2004, Jack 2000, McIntire 2005, Fabricant et al 1999

Once household resources are known, the NTP can determine whether the cost of seeking and obtaining TB care is affordable.



Graph 1 (Russell 1996):

Graph 1 shows total household resources on the Y-axis and health expenditures on the x-axis. If total costs of TB care are too high (in the shaded area), they are no longer affordable.

The Theory behind Willingness to Pay

Graph 2 shows the budget constraint, t1, reavealing the combination of goods given the patient's income and prices of goods, t1 is the patient's ability to pay (ATP). Its function is:
– (price of healthcare / price of food). M1 is the indifference curve that describes a person's preferences (willingness to pay WTP). At Point A, the person is healthy and needs little healthcare, at point B, the person is sick. With a decrease of a patient's income due to inability to work, the budget constraint shifts left, t2. Given the new budget constraint t2, the patient cannot obtain his/her desired level of consumption (point B). The intersections of the y and x axis with the budget constraint are calculated as income/price of food and income/price of healthcare.

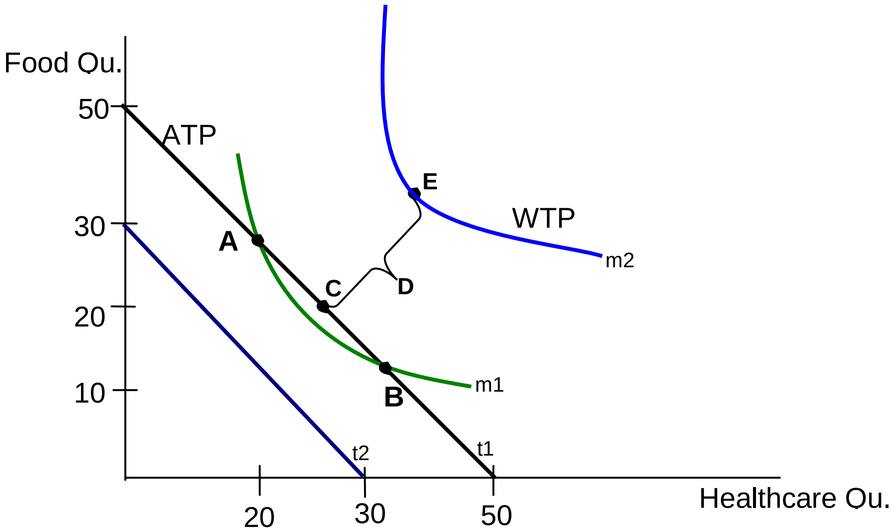
The difference D between the ability to pay (t1) and the willingness to pay (m2), is the cost of TB on the welfare of the household, including pain and suffering, so to say the true cost of TB. If the household's income decreases (t2), the difference D becomes even greater. M2 is the maximum the patient is willing to pay given his resources; t1 is the maximum the he/she is able to pay.

At the intersection of t1 with the y-axis, the patient spends 50 on food and 0 on healthcare. At the intersection with the x-axis, he spends 50 on healthcare and 0 on food. This scheme can be applied to any point in the graph. Hence, the ability to pay are all possibilities on t1, for example:

A: 20 H and 30 F = 50
B: 35 H and 15 F = 50
C: 25 H and 25 F = 50

Whereas the willingness to pay is along m2, for example E (35 H and 35 F = 70). The difference between ability and willingness to pay D is 70-50 = 20. The true cost of TB including pain and suffering is therefore 70. The method to ask for the willingness to pay is most likely the only method to capture costs of TB on household welfare and to show the difference between actual and desired consumption due to TB.

Graph 2:



This means in practice, if the NTP knows the budget of a (poor) household, the costs of treatment and the costs for food (or other items), it can see whether the costs of TB care are affordable.[10]

The **Production Function Approach** takes into account decreased productivity of chronically ill patients and decreased productivity of workers not being able to recover fully before taking up work again. The method estimates a production function of an output unit (crop land, factory, household) and by using regression analysis to evaluate the loss of output due to the illness. This model has not been used much because of the difficulty to specify and data problems. It does not capture direct costs of a disease and is therefore not of much use to estimate patients' costs.

The **Friction Cost Method** assesses indirect costs by determining the time span organizations need to restore the initial production level after production was lost due to disease (Drummond 1997, Koopmanschap et al 1995). This period differs according to level and education of the worker, location and industry. The friction cost method takes the viewpoint of the firm and of society and is therefore not useful to assess costs on patient level.

[10] The intersections of the y and x axis with the budget constraint are calculated as income/price of food and income/price of healthcare.

Summary of approaches:

Approaches to measure cost of illness	Approach	Strength	Limitation
Human Capital Method	estimates the cost to society due to morbidity and mortality of lost future productivity, discounted to the present. Cost of morbidity is the value of lost workdays.	Easy to use, since data on forgone income can be easily collected. Most widely used compared to other methods.	Doesn't capture labor substitution by family members, forgone household activities and leisure time. Use of wages as measure of productivity criticized for inaccuracy. Underestimates burden of disease on household.
Willingness to Pay	deduces the monetary value that a person associates to variations in risk of illness (or death). How much would you pay to prevent illness?	Incorporates burden to household of treatment costs, loss of productivity, cost of pain and suffering and value of forgone leisure	subject to personal interpretations of question; social desirablity bias in answering. Willingness to pay ≠ Ability to pay
Production Function	estimates a production function of an output unit and evaluates loss of output due to prevalence of illness.	Captures effect of illness on productivity also when ill people return to work before being completely cured.	difficulty to specify and to collect meaningful data. Doesn't capture direct costs of a disease.
Friction Cost Method	assesses indirect costs by determining time span organizations need to restore initial production level after production was lost due to disease.	Captures indirect costs of prevalent disease to society.	takes the viewpoint of the firm; not useful to assess costs on patient level.

Summed up, the only two methods which are applicable to measuring costs from the individual perspective, relatively easy to use and which provide meaningful data, are the Human Capital Method and the Willingness to Pay model. The limitations of these two models will need to be addressed when designing the tool.

1.4. Limitations of the review

- *HIV Coinfection*

The literature available on additional costs because of HIV coinfections is very limited. Literature on the cost of HIV/AIDS to patients during their lifetime is available, but the nature of the disease (lifelong) makes it difficult to associate these costs with costs incurred by TB patients.

- *Paediatric, unemployed and elderly TB patients and household work*

A limited number of studies (Beyers 1994, Geetharamani 2001) focus on children and economic value of housework. Most studies just capture salaries which excludes unpaid work in the household and the unemployed who lose time to seek new employment. Additional costs to a household due to elderly patients living in the same household are only captured through guardian costs of travel, accommodation and food.

- *Similar tools to improve to service delivery*

There is a multitude of studies on targeting the poor, developing measures to estimate cost burdens and socioeconomic measures, measuring access to healthcare and developing proxies for assessing income. However, the author of this review has not found any study which has reflected on the practicability, design, and impact on service delivery of such a tool for an NTP or other programs. This does not mean that such studies do not exist. Further research is needed here.

- *Comparative value*

Costs associated with seeking treatment, receiving diagnosis and the treatment itself can be divided into three phases: Costs incurred prior to diagnosis, costs incurred during diagnosis (prior to treatment) and costs incurred during treatment. It is difficult to compare study results, because of different methodological approaches and study designs. The same holds true for the distinction between the three periods in which costs are incurred. Some studies include diagnostic costs when calculating treatment costs, whereas others include diagnostic costs when assessing the pre-diagnostic burden. Therefore, studies discussing more than one period will be mentioned in both periods.

Other difficulties to compare studies include:

- **different usage of currencies**. Most studies converted results into US$. Results of three studies[11] that reported in local currencies (Thai Baht, Indian Rupees) were converted by the author of this review into US$ to allow comparison (exchange rate as reported in study, alternatively year of study). However, Dollar amounts can only give a very rough idea of costs, because of different inflation levels in each country and the value change of the US$ relative to other currencies over time, different purchasing power parities and different price levels of services.

- **different definitions and measures of direct costs** (including transport or only medical expenses). Some studies distinguished between direct expenditures and medical costs on drugs and laboratory tests. In these cases, medical expenditures were included into direct costs.

- **different definitions and measures of indirect costs** (months affected by illness or actual days off work, integration of non-remunerated work). Some studies measured indirect costs as self-reported forgone salaries, some as self-reported forgone income, some estimated forgone income on the basis of hours worked per day or per month; some used the average wage rate, some used GDP or GNI per capita, some used income levels estimated by household surveys. Some included caretaker indirect costs, though most didn't. Data is presented as percentage of monthly or annual household or per capita income. Few calculated lost productivity into forgone income. It is impossible to standardize all of these results. Hence, all numbers declared as indirect costs in these studies are compared as such. Most studies assessed indirect costs according to self-reported data collected through surveys or interviews. Coping costs are not included in indirect cost measurements, but are mentioned here separately.

- **different units of analysis** (household or per capita).

[11] Rajeswari 1999, Muniyandi 2005, Kamolratanakul 1999

2. Costs Incurred Before Diagnosis

Delays

Many studies have documented delays from the onset of symptoms to diagnosis[12]. These delays do not only increase the infectivity of a patient and lead to more serious illness[13] by the time the patient presents him/herself, but also represent a time span in which additional costs are incurred. The delay can be subdivided into the period from onset of symptoms until a patient presents him/herself at a health facility (patient delay), the period from presentation to diagnosis (diagnostic delay), the period between first visit to a health facility and diagnosis (doctor delay), the period between diagnosis and beginning of treatment (treatment delay) and the time span between first visit and start of treatment (health system delay).[14]

Onset of symptoms | **1. visit** | **Diagnosis** | **Treatment begin**

Patient Delay

Diagnostic Delay

Total Delay

Doctor Delay

Health System Delay

Treatment Delay

Studies suggest however, that the delay caused by the health system is longer than the patient caused delay[15], in Ghana especially for rural dwellers.[16] Demissie et al's (2002) study found a much shorter system delay than patient delay, but it recognizes its findings to be low compared to findings of other studies. Lonnroth et al (1999) found patient and provider delay to be more pronounced in urban areas because of more options, weak referral and coordination mechanisms.

The times of delay from onset of symptoms to diagnosis vary from study to study to a great extent, ranging from 8 weeks[17] to 19 months.[18] The majority reports time spans between 2-4 months for adults[19] and 1 month for children[20] with the number of health encounters during this time ranging between 2.7 and 6.7[21].

Direct costs

Patients repeatedly cited lack of money in general and transportation costs in particular as reasons for delay.[22] In Needham's study (2004) in Zambia, transportation costs amounted to 16% of mean monthly income. The amount of transportation varies with urban or rural location of the patient. Patients in Zambia living outside Lusaka spent twice as much on transport than those living in the proximity of or in Lusaka.[23] In his study of 687 patients in Thailand, Kamolratanakul (1999) determined the direct average cost to households between $55-225. This

[12] Kemp et al 2007, Needham et al 2001, 2004, 1998, Lawn et al 1998, Beyers et al 1994 to name just a few
[13] Gibson et al 1998, Lawn et al 1997, 1998
[14] Lawn et al 1998, Karim 2007
[15] Beyers et al 1994, Lawn et al 1998, Needham et al 2004, Squire 2005, Lonnroth et al 2001, Equi TB 2005, Lonnroth et al 2007
[16] Lawn et al 1998
[17] Needham 1998, 2004, Demissie 2002
[18] Gibson et al 1998
[19] Lawn 1998, Needham 1998, 2001, 2004, Demissie 2002
[20] Beyers 1994
[21] Equi TB 2005, Gibson et al 1998, Kemp et al 2007, Needham et al 1998, 2004
[22] Squire et al 2005, Needham et al 2004, 1998, Gibson et al 1998, Croft 1998, Muniyandi 2005
[23] Needham et al 1998

is in line with findings by Jacquet al (2006) in Haiti. Russell (2004) determines direct costs to amount to 5-21% of annual household income.

Several studies have reported pre-diagnostic costs incurred through visits to private providers, pharmacies and traditional healers.[24] Needham (2004) notes that TB infected persons in his study in Malawi paid 10% of their monthly income to traditional healers for consultation. These visits were associated with longer delays between 15 and 41 days. Lonnroth et al (2001) found that 65% of the study population in Vietnam had been treated with TB drugs by more than one provider, while 50% of patients opted for private care. The public program was perceived to be more time consuming with repeated visits for diagnostics and long-waiting times.

Indirect Costs
Most of the studies dealing with prediagnostic costs focussed on lost income, days of work lost, decreased earning ability, change in work and costs associated with coping strategies.[25] Indirect cost estimates range from $16[26] (Malawi, Bangladesh, India, Zambia) to $68[27] (Malawi, Zambia). In these studies, workdays lost range from 18[28] to 48[29] (both Zambia) for patients and 9 to 13[30] for guardians. Muniyandi (2005, India) reports 71% of patients borrowing money to cope with costs. Croft (1998, Bangladesh) reports similar findings with half of her study population coping by selling land and livestock or taking out a loan.

Total Costs
Total costs (direct and indirect) for patients prior to diagnosis, measured as % of mean monthly income, varies between 127% (Needham et al 1998) and 135% (Kemp et al 2007). In Dollar terms, this amounts to 59 and 29 US$ respectively. Lonnroth et al (2001) found total costs to lie between 15 and 77 US$. Needham (1998) found caregiver costs to amount to 31% of mean monthly income. Striking is the difference between costs expressed in mean monthly income between the poor and non-poor in Malawi.[31] Whereas the poor have associated costs amounting to 244% of their monthly income on accessing diagnosis, the non-poor's burden amounts to 129%. Needham (1998) reports economic loss to be especially grave for self-employed persons.

Studies consulted on pre-diagnostic costs:

Beyers et al (1994). Delay in the diagnosis, notification and initiation of treatment and compliance in children with tuberculosis. Tuberc Lung Dis 75, 260-265.

Boillot & Gibson (1995). The formal and informal costs of tuberculosis in Sierra Leone, TuberLungDis 76, supplement 2, 114.

Croft & Croft (1998). Expenditure and loss of income incurred by tuberculosis patients before reaching effective treatment in Bangladesh. Int J Tuberc Lung Dis 2, 252-254.

Demissie et al (2002). Patient and health service delay in the diagnosis of pulmonary tuberculosis in Ethiopia. BMC Public Health 2(23).

[24] Kemp et al 2007, Muniyandi 2005, Lonnroth et al 2001, Needham et al 2004
[25] Kemp et al 2007, Muniyandi 2005, Croft 1998, Needham 1998, 2004
[26] Kemp et al 2007, Needham 1998
[27] Jacquet et al 2006
[28] Needham et al 1998
[29] Needham et al 2004
[30] Kemp et al 2007
[31] Kemp et al 2007

EQUI-TB Knowledge Programme (2005). Barriers to accessing TB care: how can people overcome them? Liverpool School of Tropical Medicine.

Floyd et al (2006). Cost and cost-effectiveness of PPM-DOTS for tuberculosis control: evidence from India. Bull World Health Organ 84(6), 437-45.

Gibson et al (1998). The cost of tuberculosis to patients in Sierra Leone's war zone. Int J Tuberc Lung Dis 2(9), 926, 731.

Jacquet et al (2006). Impact of Dots Expansion on tuberculosis related outcomes and costs in Haiti. BMC Public Health 6, 209.

Kemp et al (2007). Can Malawi's poor afford free tuberculosis services? Patient and household costs associated with a tuberculosis diagnosis in Lilongwe. Bulletin of the WHO 85, 580-585.

Kamolratanakul et al. (1999). Economic impact of tuberculosis at the household level. Int J Tuberc Lung Dis 3,596-602.

Karim et al (2007). Gender differences in delays in diagnosis and treatment of tuberculosis. Health Policy & Planning 22, 329-334.

Lambert (2005). Delays to treatment and out-of-pocket medical expenditure for tuberculosis patients, in an urban area of South America. Ann Trop Med Parasitol.99(8), 781-7.

Lawn et al (1997). Pulmonary tuberculosis: diagnostic delay in Ghanaian adults. Int Jour Tub & Lung Dis 2, 635-640.

Lonnroth al (2001). Can I afford free treatment? Perceived consequences of health care provider choices among people with tuberculosis in Ho Chi Minh City, Vietnam. Soc Sci Med 52, 935-948.

Lonnroth et al (2007) Social franchising of TB care through private GPs in Myanmar: an assessment of treatment results, access, equity and financial protection. Health Policy and Planning 22, 156-166.

Muniyandi (2005). Costs to patients with tuberculosis treated under DOTS programme. Indian J of Tub 52, 188-196.

Needham et al (2001). Socio-economic, gender, and health services factors affecting diagnostic delay for tuberculosis patients in urban Zambia. Trop Med Int Health 6, 256-259.

Needham (1998). Barriers to tuberculosis control in urban Zambia: the economic impact and burden on patients prior to diagnosis. Int J Tuberc Lung Dis 2, 811-7.

Pantoja et al (forthcoming). Free TB treatment at a high cost: economic burden faced by TB patients in a public-private mix initiative in Bangalore, India.

Squire et al. (2005) Lost smear positive pulmonary tuberculosis cases; where are they and why did we lose them? Int J Tub and Lung Dis 9(1), 25-31.

Zhang et al (2007). Persistent problems of access to appropriate, affordable TB services in rural China: experiences of different socio-economic groups. BMC Public Health 7, 19.

3. Costs During Diagnosis / Pre-Treatment

Costs specifically measured for diagnosis are difficult to discern and rarely addressed by themselves. Most studies combine the assessment of diagnostic costs with costs occurring before diagnosis or during treatment. Netherless, if costs occurring at the diagnostic stage were reported separately in studies, they are reported here as well.

Delays

Two studies in Malawi and Bolivia[32] looked specifically at pretreatment delays, which includes the delay before diagnosis. Lambert et al (2005) found pretreatment delays to be mostly due to the provider (14 weeks) and less due to the patient (9 weeks), with an average total of 12.6 weeks. Lonnroth et al (2007) reports 15 days delay from first contact with the health system to treatment due to the provider and a total of 26 days (3.7 weeks) from onset of symptoms to treatment start. Kemp et al (2007) in Malawi found that 4.5-6 visits to health centers were necessary before treatment was started.

Direct costs

Direct costs incurred during diagnosis range widely, per household between $2 in Tanzania[33] and $57 in Thailand[34], and per patient between $6 in India[35] and $130 in Bangladesh[36]. The majority lies between $10-50. Russell (2004) found pre-+post-diagnosis direct costs to amount to 8-13% of annual household income.

Cases of overprescriptions, charges for drugs (India) and informal payments occur (China, Sierra Leone and Tajikistan)[37], though this seems to depend strongly on the setting. Kemp et al (2007) found informal payments to be rare in Malawi. In China, often-times patients are charged for additional, unnecessary drugs and diagnostic tests leading to a substantial increase of the costs to patients (personal communication).

Indirect costs

Indirect costs similarly have a wide-spread range between $16 in Malawi[38] and $115 in Bangladesh[39], with the majority lying between $10-30, however only three studies specify indirect costs incurred exclusively at the diagnostic stage. Workdays lost up to diagnosis lie between 20[40] and 48 days[41].

Total Costs

A better picture emerges when looking at total costs incurred during diagnosis. Here, the majority lies between $10 and 30, but reports are going all the way up to $245 in Bangladesh.[42] Total costs as a percentage of income are 135% of mean monthly household income in Malawi[43] and 31% of annual income per capita in Bangladesh[44], 58% for the poor in Myanmar[45].

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[32] Kemp et al 2007, Lambert et al 2005
[33] Wyss et al 2001
[34] Kamolratanakul 1999
[35] Rajeswari 1999
[36] Croft & Croft 1998
[37] Gibson et al 1998, Equi-TB 2005, Muniyandi 2005, Boillot & Gibson 1995, Falkingham 2003
[38] Kemp et al 2007
[39] Croft & Croft 1998
[40] Kemp et al 2007
[41] Rajeswari 1999
[42] Ibid
[43] Kemp et al 2007
[44] Croft & Croft 1998

Interestingly, Kemp et al (2007) found that the poor spent 244% of monthly income on diagnosis which is 110% more than the average. This emphasizes the fact, that averages do not adequately represent the economic burden of the poor.

Studies consulted on diagnostic / pre-treatment costs:

Boillot & Gibson (1995). The formal and informal costs of tuberculosis in Sierra Leone, TuberLungDis 76(supplement 2), 114.

Croft & Croft (1998). Expenditure and loss of income incurred by tuberculosis patients before reaching effective treatment in Bangladesh. Int J Tuberc Lung Dis 2, 252-254.

EQUI-TB Knowledge Programme (2005). Barriers to accessing TB care: how can people overcome them? Liverpool School of Tropical Medicine.

Falkingham (2003). Poverty, out-of-pocket payments and access to health care: evidence from Tajikistan. Social Science & Medicine 58, 247-258.

Gibson et al (1998). The cost of tuberculosis to patients in Sierra Leone's war zone. Int J Tuberc Lung Dis 1998, 2(9), 926,731.

Kamolratanakul et al. (1999). Economic impact of tuberculosis at the household level. Int J Tuberc Lung Dis 3,596-602.

Kemp et al (2007). Can Malawi's poor afford free tuberculosis services? Patient and household costs associated with a tuberculosis diagnosis in Lilongwe. Bulletin of the WHO 85, 580-585.

Lambert et al.(2005). Delays to treatment and out-of-pocket medical expenditure for tuberculosis patients, in an urban area of South America. Ann Trop Med Parasitol.99(8), 781-7.

Lonnroth et al (2007). Social franchising of TB care through private GPs in Myanmar: an assessment of treatment results, access, equity and financial protection. Health Policy and Planning 22, 156-166.

Lonnroth et al (1999). Delay and discontinuity - a survey of TB patients' search of a diagnosis in a diversified health care system. Int J Tuberc Lung Dis 3(11), 992-1000.

Muniyandi (2005). Costs to patients with tuberculosis treated under DOTS programme. Indian J of Tub 52, 188-196.

Rajeswari et al (1999). Socio-economic impact of tuberculosis on patients and family in India. Int J Tuberc Lung Dis 3, 869-77.

Uplekar (1996). Tuberculosis patients and practitioers in private clinics. Bombay: the foundation for research in community health.

Wyss et al (2001). Cost of tuberculosis for households and health care providers in Dar es Salaam, Tanzania. Trop Med Int Health 6, 60-8.

[45] Lonnroth et al 2007

4. Costs During Treatment

Delays

A multitude of studies deals with treatment delays (capturing patient and system delay) defined as the time elapsed from onset of symptoms until the beginning of treatment. Results from studies that looked at patient costs found treatment delays (capturing herein also prediagnostic and diagnostic delay) to lie between 6 and 16 weeks.[46] Taking into account however that prediagnostic delays alone were reported to last already between 5 and 17 weeks, treatment delays should theoretically exceed prediagnostic delays, assuming that time elapses between diagnosis and start of treatment. On the other hand, these numbers provide us at least with a time frame of 5-17 weeks in which we can assume that the patient incurrs costs due to forgone income because of his/her inability to work and time lost during his/her efforts of seeking treatment.

Direct costs

Direct costs vary widely across studies which depends of course on local prices for food, transport etc. Starting from $5 in Tanzania[47] up to $150 in Haiti[48], with the majority between $20 and 50. Items requiring most of the expenditures are travel and food and for drugs if they are not provided for free.[49] In India[50], expenditures on health visits, travels and drugs were found to be higher among urbanites than among patients living in rural areas. In South Africa, Sinanovic (2003) identified DOT visits to be the item accumulating most of the costs. She further found that workplace supervision was much less costly ($11) than clinic supervision ($111). In India[51], direct costs were found to be higher for women than for men.

In Thailand, out-of-pocket direct expenditures of the very poor for diagnosis and treatment amounted to 15% of their annual per capita income,[52] in Haiti, they were 49%.[53]

Medical expenses amounted to 40% of annual income of Chinese households, for low-income households, they were equivalent to 112% of annual income[54]. Russell (2004) determined direct post-diagnosis costs to amount to 18.4% of annual household income. Moalosi (2003) investigated in Botswana direct costs for care-givers and found that home-based care cost 23% less for care givers than hospitalization.

Hospitalization:

Floyd et al (1997) found that the average length of hospital stay for patients in South Africa was 17.5 days for those patients entering community DOT after discharge and two months for conventional hospitalization during the intensive phase. Admission to hospital constituted 76% of patient cost, with a day in hospital costing the patient $4. DOT at hospital was more expensive than DOT at health clinic or community level. A hospital visit cost the patient 5 hours. Okello et al (2003) had similar results in Uganda: one day hospital cost $1.30 for the patient, overall, hospital based care was more expensive than community based care ($252 vs $206). Moalosi et al (2003) found home-based care in Botswana to be 42% cheaper for patients than hospital-based care; while the average hospital stay with home-based care was 21 days, it was 93 days with hospital-based care. Needham (1998) found caregiver costs to be greater for in-patients than for

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[46] Lambert et al 2005, Lonnroth et al 1999, Lienhardt et al 2001, Rajeswari 2002, Lawn et al 1998
[47] Wandwalo 2005
[48] Jacquet et al 2006
[49] Kamolratanakul 1999, Wyss et al 2001, Sinanovic 2003
[50] Rajeswari et al1999
[51] Rajeswari et al 1999
[52] Kamolratanakul 1999
[53] Jacquet el al 2006
[54] Zhang et al 2007

out-patients, in his 2004 study however, he attributes less delays for patients seeking hospitalization.

Indirect costs
Indirect costs in Dollar terms amount to $7[55] - $50[56], with a tendency towards $20[57]. Productivity in household or occupation drops by ca 30%. $150-200 or 15%-20% of annual household income is lost; patients cannot work for ca 2-4 months and 20-75% of patients incur some form of debt.

<u>Summary:</u>

Direct Cost as % of income: Household: 18 -112%
Per capita: 15% - 49%

Indirect Costs:

Productivity
- Household activities and childcare falls by 30%-40%
- 74% loss of working capacity

Income
- loss of 2-45% of annual household income (majority ca. 15%)
- 9-112% of annual per capita income (majority 10-30%)
- 15-89% of GDP/capita (majority ca 15%)

Work time lost:
- 2 -14 months (majority 2-4 months)
- One person per household cannot follow an occupation during period of illness

Coping costs:
- 11% of children discontinued school, 8% took up employment (India, Geetharamani 2001)
- 55 – 75% of patients or households borrow money or incur other forms of debt

Total Costs
Total costs (direct and indirect) of TB treatment to patients are reported to be between $9.5[58] and $202[59], with the majority being below $100[60]. Total cost of TB treatment is found to be between 20 and 30% of annual household income.[61] Sinanovic (2003) found community based care more affordable than clinic based care (due to DOT visits). Wandwalo's (2005) cost-effectiveness study in Tanzania supports this finding. On average, ss+ patients had to make 58 visits to a health facility for DOT, a ss- had a total of 24 visits, compared to a patient under community DOT with a total of 10 visits.

Studies consulted on treatment costs:

Ahlburg (2000). The economic impact of TB: ministerial conference Amsterdam, WHO.

[55] Wandwalo 2005
[56] Jacquet et al 2006
[57] Wandwalo 2005, Muniyandi et al 2005
[58] Gibson et al 1998
[59] Jacquet et al 2006
[60] Muniyandi et al 2005, Uplekar 1996, Wandwalo et al 2005, Rajeswari et al 1999
[61] Ramachandran et al 1997, Croft & Croft 1998

Croft & Croft (1998). Expenditure and loss of income incurred by tuberculosis patients before reaching effective treatment in Bangladesh. Int J Tuberc Lung Dis 2, 252-254.

Fryatt (1997). Review of published cost-effectiveness studies on tuberculosis treatment programmes. Int J Tuberc Lung Dis 1(2),101-109.

Floyd et al (1997). Comparison of cost-effectiveness of directly observed treatment and conventionally delivered treatment for tuberculosis: experiences from rural South Africa. BMJ 315(7120), 1395-6.

Geetharamani et al (2001). Socio-economic impact of parental tuberculosis on children. Ind J Tub 48, 91-94.

Gibson et al (1998). The cost of tuberculosis to patients in Sierra Leone's war zone. Int J Tuberc Lung Dis 1998, 2(9), 926, 731.

Jacquet et al (2006). Impact of Dots Expansion on tuberculosis related outcomes and costs in Haiti. BMC Public Health 6, 209.

Kamolratanakul et al (1999). Economic impact of tuberculosis at the household level. Int J Tuberc Lung Dis 3,596-602.

Lambert et al (2005). Delays to treatment and out-of-pocket medical expenditure for tuberculosis patients, in an urban area of South America. Ann Trop Med Parasitol.99(8), 781-7.

Lonnroth et al (2007). Social franchising of TB care through private GPs in Myanmar: an assessment of treatment results, access, equity and financial protection. Health Policy and Planning 22, 156-166.

Lonnroth et al (1999). Delay and discontinuity - a survey of TB patients' search of a diagnosis in a diversified health care system. Int J Tuberc Lung Dis 3(11), 992-1000.

Lienhardt et al (2001). Factors affecting time delay to treatment in a tuberculosis control porgramme in a sub-saharan african country: the experience of the Gambia. Int.Jour of Tub and Lung Dis 5, 233-239.

Lawn et al (1997). Pulmonary tuberculosis: diagnostic delay in Ghanaian adults. Int Jour of Tub and Lung Dis 2, 635-640.

Moalosi et al (2003). Cost-effectiveness of home-based care versus hospital care for chronically ill tuberculosis patients, Francistown, Botswana. Int J Tuberc lung Dis 7, 80-5.

Muniyandi (2005). Costs to patients with tuberculosis treated under DOTS programme. Indian J of Tub 52, 188-196.

Okello et al (2003). Cost and cost-effectiveness of community-based care for tuberculosis patients in rural Uganda. Int J Tuberc Lung Dis 7(9), 72-79.

Rajeswari al (1999). Socio-economic impact of tuberculosis on patients and family in India. Int J Tuberc Lung Dis 3, 869-77.

Ramachandran et al (1997). Economic impacts of tuberculosis on patients and family. Tuberculosis Research Centre, Indian Council of Medical Research, Chennai, South India.

Russell (2004). The economic burden of illness for households in developing countries: a review of studies focusing on Malaria, Tuberculosis and Human Immunodeficiency Virus/Acquired Immunodeficiency syndrome. Am J Trop Med Hyg 71 (Suppl2), 147-155.

Saunderson (1995). An economic evaluation of alternative program designs for tuberculosis control in rurual Uganda. Social Science and Medicine 40, 1203-1212.

Sinanovic et al (2003). Cost and cost-effectiveness of community-based care for tuberculosis in Cape Town, South Africa. Int J Tuberc Lung Dis 7(9), 56-62.

Uplekar (1996). Tuberculosis patients and practitioers in private clinics. Bombay: the foundation for research in community health.

Wandwalo et al (2005). Cost and cost-effectiveness of community based and health facility based directly observed treatment of tuberculosis in Dar es Salaam, Tanzania. Cost Eff Resour Alloc. 14, 3-6.

Wyss et al (2001). Cost of tuberculosis for households and health care providers in Dar es Salaam, Tanzania. Trop Med Int Health 6, 60-8.

Zhang et al (2007). Persistent problems of access to appropriate, affordable TB services in rural China: experiences of different socio-economic groups. BMC Public Health 8(7), 19.

5. **Total Costs** (Pre-Diagnosis, Pre-Treatment, Treatment)

In order to assess the costs of a complete treated TB episode relative to its parts, it is useful to review studies that have investigated the total costs of TB treatment while including costs incurred at each level. Two reviews by Ahlburg (2000) and Russell (2004) are particularly useful.

Direct costs
Direct costs vary again strongly by country, starting with $24 in Zambia[62] up to $346 in China[63]. It can be observed however that the most frequent dollar range is between $60 and 130[64]. Direct costs of TB amount to 3.7 – 15% of annual income (highest for the poor).[65] In comparison, Jackson (2006) found that direct costs to be equivalent to 55% of annual household income in China. Direct cost burdens are exacerbated by widespread use of private providers, particularly in urban settings.[66] In addition, direct costs are unevenly distributed across households, minorities bearing high costs compared to the majority of the population.[67] Russell (2004) attributes more meaning to median figures than to mean figures, however, mean figures are mostly presented in the literature. Costs vary strongly and the mean is therefore determined by outliers.

Indirect costs
Indirect costs vary between $28[68] and $1384[69] with the majority lying in the range of $100-500[70]. Russell found TB indirect costs to amount to 5-8% of annual household income, Rajeswari (1999) to 26%. In terms of workdays lost, Needham (1996) reports 2 weeks in Zambia whereas others

[62] Needham et al 1996
[63] Jackson et al 2006
[64] Russell 2004, Rajeswari 1999, Kamolratanakul 1999, Ahlburg 2000
[65] Kamolratanakul 1999, Rajeswari 1999, Russell 2004
[66] Russell 2004
[67] Russell 2004
[68] Russell 2004
[69] Wyss 2001
[70] Russell 2004, Rajeswari 1999, Kamolratanakul 1999, Wyss et al 2001, Jackson et al 2006, Jacquet et al 2006, Ahlburg 2000

report an average loss of 8 -12 weeks[71]. Interestingly, according to Ahlburg (2000), treated patients lose 2 months of work compared to untreated ones losing 12 months. In respect to coping costs, Jackson (2006) reports 66% of patients borrowing money from relatives or friends, 45% sold assets and 8% borrowed money from banks. Rajeswari (1999) reports 14% of annual household income forgone for debt redemption.

Total Costs

The economic burden of TB can be well-understood with the help of % of income. The poor spend a far greater proportion on meeting basic needs (food etc) whereas the non-poor have more disposable income. The burden of each $ spent is significantly higher for the poor. Russell (2004) deems a cost burden of more than 10% of annual household income to be already catastrophic for a household's financial situation. Taking this into account, study results point to the enormous burden of households and individuals of 20-30% of monthly income[72] and 10-90% of annual household income[73] (highest for the very poor), the majority being approximately between 10% and 40%[74]. Ahlburg (2000) determined the cost of morbidity of treated TB to be 15% of GDP per capita.

Studies consulted on Total TB costs for patients:

Ahlburg (2000). The economic impact of TB: ministerial conference Amsterdam, WHO.

Jacquet et al (2006). Impact of Dots Expansion on tuberculosis related outcomes and costs in Haiti. BMC Public Health 6, 209.

Jackson et al (2006).Poverty and the economic effects of TB in rural China. Int J Tuberc Lung Dis.10(10), 1104-10.

Kamolratanakul et al. (1999). Economic impact of tuberculosis at the household level. Int J Tuberc Lung Dis 3, 596-602.

Muniyandi (2005). Costs to patients with tuberculosis treated under DOTS programme. Indian J of Tub 52, 188-196.

Needham (1996). Economic barriers for TB patients in Zambia. The Lancet 348(9020), 134-5.

Rajeswari et al (1999). Socio-economic impact of tuberculosis on patients and family in India. Int J TUberc Lung Dis 3, 869-77.

Russell (2004). The economic burden of illness for households in developing countries: a review of studies focusing on Malaria, Tuberculosis and Human Immunodeficiency Virus/Acquired Immunodeficiency syndrome. Am J Trop Med Hyg 71 (Suppl2),147-155.

Wyss et al (2001). Cost of tuberculosis for households and health care providers in Dar es Salaam, Tanzania. Trop Med Int Health 6, 60-8.

[71] Rajeswari 1999, Kamolratanakul 1999, Ahlburg 2000
[72] Needham et al 1996, Muniyandi et al 2005
[73] Russell 2004, Rajeswari 1999, Jacquet et al 2006, Ahlburg 2000
[74] Russell et al 2004, Kamolratanakul 1999, Ahlburg 2000, Rajeswari 1999

6. TB/HIV Coinfection costs

There are plenty of studies on mortality cost of HIV deaths to society, but there is hardly any literature on costs for TB patients that are coinfected with HIV. Jacquet et al (2006) bases the time range in which there is a loss of productivity on the number of years anticipated to survive after development of active TB and number of years survived with HIV infection before developing active TB, with a total average survival of 9.8 years. In his review study, Beck et al (2001) reports a community loss of 0.4 potential years of life lost per person in India; In Uganda, incremental lost income per person with Aids death was $12.256 in 1992. With the lack of studies on this topic, the incremental costs of an HIV coinfection are difficult to determine. In terms of indirect costs, greater mortality, lower productivity, long-term reduced ability to earn and prolonged morbidity of TB-HIV coinfected persons are definite, especially if the patient presents him/herself late.[75] Annex I specifies extra cost items due to an HIV infection.

7. Gender

A number of studies emphasize higher costs for women than for men. Women take longer to seek care (patient delay) [76] due to stigma and social exclusion, heavier workloads, prioritization of other family members over own well-being, lack of independence, inaccessibility to financial resources and powerlessness in decision-making[77]; they experience longer provider, diagnostic and treatment delays[78]; they are engaged in more activities that need to be replaced in the household, while girls replace these activities more than boys[79]. In addition, women have higher direct costs than men, because they often need somebody to accompany them[80], they are less mobile and have less financial resources[81] and women experience greater loss of income probably because of more lost work days[82].

Studies consulted on TB-HIV Coinfection costs and Gender

Currie et al (2005). Cost, affordability and cost-effectiveness of strategies to control tuberculosis in countries with high HIV prevalence. BMC Public Health 5, 130.

Beck et al (2001). The cost of HIV treatment and care. A global review. Pharmacoeconomics 19(1), 13-39.

Jacquet et al (2006). Impact of Dots Expansion on tuberculosis related outcomes and costs in Haiti. BMC Public Health 6, 209.

Lawn et al (1997). Pulmonary tuberculosis: diagnostic delay in Ghanaian adults. Int Jour Tuber & Lung Dis 2, 635-640.

Needham et al (2001). Socio-economic, gender, and health services factors affecting diagnostic delay for tuberculosis patients in urban Zambia. Trop Med Int Health 6, 256-259.

[75] Lawn et al 1997
[76] Equi-TB 2005, Needham 2001, Karim et al 2007
[77] Lawn et al 1998, Needham 2001, Karim et al 2007
[78] Needham et al 2001, Karim et al 2007
[79] Kemp et al 2007
[80] Muniyandi 2005
[81] Needham 2001
[82] Needham 1998

Karim et al (2007). Gender differences in delays in diagnosis and treatment of tuberculosis. Health Policy & Planning 22, 329-334.

8. Summary of Study Results

Pre-Diagnostic costs:

Delay:	2-4 months, 3-7 health encounters
Direct costs:	$55-225, 5-21% of annual household income
Indirect costs:	$16-68, 18-48 days lost
Total:	127 per capita -135% household mean monthly income

Types of costs (direct):

- Travel, food, accommodation during visits to care givers for seeking help in private and public sector including pharmacies, traditional healers etc.
- Expenditures on medicines, special foods, tests

Indirect:

- Income reduction due to missed work days/hours, lost job, loss of time to seek job, uptake of less paid labor due to illness
- reduced household activities (or cost of other household member replacing household work)
- missed work for caretaker
- decreased productivity
- coping costs: use of savings, reduction of food intake, assets are sold, extra job, kids drop out of school to work, debt / loans

Diagnosis/Pre-treatment costs:

Delay:	3 months (including pre-diagnosis), 5 health encounters
Direct costs:	$10-50, 8-13% of annual household income
Indirect costs:	$10-30, 20-48 days lost
Total:	ca 135% mean montly household income, ca 31% annual income per capita

Types of costs (direct):

- travel forth and back for tests and receiving test results
- accommodation
- food and “special foods”
- guardian costs
- diagnostic tests (if not provided for free)
- additional informal payments
- charges for drugs
- user fees
- ‘under the table’ fees

Indirect:

- Income reduction due to missed work days/hours, lost job, loss of time to seek job, uptake of less paid labor due to illness
- reduced household activities (or cost of other household member replacing household work)
- missed work for caretaker
- decreased productivity
- coping costs: use of savings, reduction of food intake, assets are sold, extra job, kids drop out of school to work, debt / loans

Treatment costs:

Delay: 1 ½ - 4 months (incl pre-diagnostic and diagnostic delays), total of 5-17 weeks
Direct costs: $20-50, 15-49% of annual per capita income, 40-112% of annual household income
Indirect costs: ca $20, 2-4 months of lost work, 15-20% annual household income, 20-75% of patients incur debt, productivity loss of 30%
Hospitalization: 17 – 21 days home-based care; 60-93 days hospital care, $1.3 – 4 per day
Total: below $100, 20-30% of annual household income

Types of costs (direct):

- Costs due to hospitalization
- Travel, food, accommodation for follow up tests
- Travel, food for DOT visits (if applicable)
- Travel, food for medicine collection visits (if applicable)
- Consultation / user fees (if applicable)
- Guardian costs
- Informal payments (if applicable): additional diagnostic tests, drugs
- Additional costs due to parallel treatment sought by other providers
- Additional costs for TB-HIV coinfected patients: travel and food to ARV clinic, screening intake, test result, medicine collection
- health insurance up front payments to be reimbursed later (if applicable)

Indirect:

- Income reduction due to missed work days/hours, lost job, loss of time to seek job, uptake of less paid labor due to illness
- reduced household activities (or cost of other household member replacing household work)
- missed work for caretaker
- decreased productivity
- coping costs: use of savings, reduction of food intake, assets are sold, extra job, kids drop out of school to work, debt / loans

Total Costs TB episode:

Direct costs: $60-130, 4-15% of annual per capita income
Indirect costs: $100-500, 5-16% of annual household income, 2-3 months lost work, 70% borrow
Total: 20-30% of monthly income (household and per capita), 10-90% of annual household income, 15% of GDP/capita

It can be clearly seen that costs (indirect and direct) incurred at the prediagnostic stage are higher than during the following stages. Delays in the prediagnostic stage are most costly for the patient and society, for the patient is still infectious and his/her health and productivity are deteriorating. Direct costs frequently pass the 10% of household income and Indirect costs often exceed direct costs. This has been shown by an influential review study on household costs due to illnesses.[83] For direct costs, the **most expensive items are travel (especially DOT visits to health facilities), food and private sector charges**. **In total, TB patients lose 2-4 months of income because of the inability to work, mostly during the treatment phase.**

Coping Costs
In regard to coping costs, two studies[84] have summarized the order of coping strategies used by patients and neatly complement the findings presented in this review. They both found that the

[83] McIntire 2006
[84] Sauerborn 1996, McIntire 2006

household first reallocates tasks. Second, savings (if any) are used; third, consumption is reduced (mostly food); fourth, assets are sold (land, livestock); fifth, loans are taken up and last, income is diversified (additional job); the community is asked for help as a last resort. This means on the one hand, that the household would be a more suitable unit of analysis and on the other, that debt (and interest payments) is not inherently the logical consequence of cost constraints. The sale of assets however reduces future income and therefore TB can stand in the beginning of a spiral into deeper poverty.

Summed up, costs to patients depend on:

- The nature, frequency and duration of the illness
- The healthcare seeking behaviour of affected individuals
- The type of treatment (community vs health facility DOT)
- The direct and indirect costs of diagnosis and treatment
- Responses and mobilization of resources
- Resources available to the household or patient

9. Methodological Issues In Designing The Tool

9.1. Income Indicator Usage

In order to estimate the impact costs have on a patient, we first need to know the amount that a patient can afford to spend on TB. That is, we need to be able to judge what % of the patient's income is associated with costs of TB. There are two ways to approach this: either to ask patients with the means of surveys and interviews about their income or consumption expenditures or to use standardized measures of income, such as average wage rates, GNI per capita, or income levels. These standardized measures are usually obtained through household surveys or data supplied by UNDP, the World Bank[85], UNICEF[86], DHS[87] or WHO[88]. However, these databases do not provide recent income data on all countries.

For the purpose of developing a tool for NTP managers to estimate patient costs, both approaches face difficulties. The bottom-up approach requires substantial financial and human resources to conduct representative surveys. During the past years, researchers have become more and more hesitant to use self-reported income data and found asset based assessments households surveys more useful and representative.[89] The top-down approach is more practical, but average wage rates and GNI/capita don't provide the NTP with information specifically about the most vulnerable parts of the population, that this tool aims to target; they only represent averages and therefore underestimate the poor's burden[90]. A good and often used alternative is

[85] Gwatkin et al 2007: Socio-economic differences in health, nutrition and population. World Bank.http://www1.worldbank.org/prem/poverty/health/ World Development Report 2006: Selected development indicators http://www-wds.worldbank.org/external/default/WDSContentServer/IW3P/IB/2005/09/20/000112742_20050920110826/additional/841401968_2005082630000823.pdf
[86] UNICEF Multiple Indicator Cluster Surveys: http://www.childinfo.org/MICS2/natlMICSrepz/MICSnatrep.htm
[87] Demographic and Health Survey DHS: http://www.measuredhs.com/countries/start.cfm
[88] WHO/World Health Surveys: www.who.int/healthinfo/survey/en/index.html
[89] Verbal communication with researchers from McGill and Liverpool School of Tropical Medicine
[90] Russell 1996

recent data on household incomes obtained through country-level household surveys. Not every country has conducted such surveys, for they are expensive.[91]

Researchers have struggled with these problems and found different solutions. Filmer (2001) determined household assets (in India) to be closely enough related to consumption expenditures to serve as a proxy for the latter. Hence, surveys not on income, but on assets or consumption may serve the same purpose. Zhang et al (2007) used the indicator 'annual household medical expenditures during the last 12 months' as a proxy for estimating the costs for diagnosis and treatment. Fabricant et al (1999) used housing type, food expenditure and self-estimates as proxies for income levels in Sierra Leone and found that a one-day agricultural wage correlates with the average price of an out-patient visit in some countries and therefore serves as an indicator for affordable treatment.

Another difficult issue, and therefore often-times left out, is the method to estimate loss of income for individuals active in the household, but not in regular employment or waged activities. Recalling what was said on coping strategies, it is known, that in the short-run, activities are reallocated within the household.[92] In the long-run, however, they will need to be replaced. Drummond (1997) recommends either using the average wage, the cost of replacing the role, or the opportunity cost of production the individual could have contributed to, if he/she was employed. These measures however run the risk of overestimation.

Summed up, what needed is:

- Household or per capita income data (for the poorest quintile and average)
- cost as % of hh & per capita income (derived by household data and cost data)
- willingness to pay / affordability of services

9.2. Income data

Since we are trying to assess the impact of costs on the lowest income quintile of the population, the question remains which income measure to use. There is a whole body of literature on measuring poverty which addresses the same question (from a different angle). There are three basic approaches:

1) Real measures:
    a. **National household budget surveys** – dependent on availability from national statistics office. Whether any surveys have been conducted recently can be seen by searching the International Household Survey Network (IHSN) database[93].
    b. **UNDP Human Development reports** [94] (detailed reports on national situations, distinguishing between urban and rural and by districts, giving information on real per capita expenditure in local currency, adjusted to Purchasing Power Parity).
    c. For Africa, the **Africa Development Indicators** 2006[95] provide recent detailed data.
    d. World Bank **Povcalnet data** by country on average monthly income, headcount of population living in poverty, Gini index[96] Compare this data with GNI/capita and poverty line of 1$ a day.

[91] It is argued that household surveys don't include the poorest of the poor, because many households in urban slums are not interviewed, and where it is considered to be risky or difficult to identify household entities (UN Research Institute for Social Development 2007)

[92] Drummond 1997

[93] http://www.surveynetwork.org/home/?lvl1=activities&lvl2=catalog&lvl3=surveys

[94] http://hdr.undp.org/en/

[95] Household surveys p103ff http://siteresources.worldbank.org/INTSTATINAFR/Resources/ADI_2006_text.pdf

e. **Living Standards Measurement Studies**[97] by the World Bank provide datasets of household surveys for many countries and guidelines for interpreting this data.
f. **Gross national income per capita** for each country by World Bank[98]. If Gini coefficient (from Povcalnet) is low, GNI/capita can be used, don't use it with a high Gini. If % of population living below poverty line is small, GNI/capita can be used, otherwise don't use it.
g. **Gross domestic product per capita** for each country by UN Statistics Division on social indicators[99]
h. **ILO reports** on wages of unskilled/agricultural labor[100] per country

2) Absolute estimates:
   a. Absolute Poverty line: World Bank measures of absolute poverty: **1$ a day** (31 $ per month) at purchasing power parity. This can be compared to GNI/capita and mean monthly income on Povcalnet. If they are similar, GNI/capita can be used. If they are very different, don't use GNI/capita.
   b. **Basket of goods** (minimum necessities): food vs. non-food items – dependent on availability from national statistics office or also in Human Development Reports

3) Relative estimates:
   a. Relative Poverty lines: These are usually set at **50-70% of median household income**[101]. GNI could be used as baseline as well. If Gini coefficient is low, this measure can be meaningful, not so with a high Gini.[102]

With all of these measures, the most recent and meaningful data should be taken;

Prioritization:
1) Recent (5 years or less old) **national household surveys** specifying income data according to geographical location or income quintiles of the population
2) For Africa: the **Africa Development Indicators** 2006, for the rest of the world **Human Development report** data
3) If none of the above are recent or available, compare GNI/capita, GDP/capita with World Bank poverty line and relative poverty line (60% of median or average household income), taking into account % of population living below poverty line and Gini coefficient. Make meaningful choice which one to use.
4) If available, take unskilled or agricultural wage from ILO database per country.

Example: Rwanda:

1) IHSN search yields no result.
2) Search on National institute of Statistics Rwanda website yields no result.
3) Search in Africa Development Indicators 2006 yields no result (country not listed)
4) Search on Human Development Report website yields following result: National Report Rwanda 2007

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96 http://iresearch.worldbank.org/PovcalNet/jsp/index.jsp
97 http://www.worldbank.org/LSMS/
98 http://web.worldbank.org/WBSITE/EXTERNAL/DATASTATISTICS/0,,contentMDK:20535285~menuPK:1390200~pagePK:64133150~piPK:64133175~theSitePK:239419,00.html
99 http://unstats.un.org/unsd/demographic/products/socind/inc-eco.htm
100 http://laborsta.ilo.org/
101 Combat Poverty Agency 2006, OECD
102 Cut off points for high and low Ginis could be (arbitrarily taken) at 20. Low Gini <20; high Gini >20

- P. 15ff: Reaching the poor, p.19: average income in bottome quintile in 2006: Rwf18,900 /year
- P. 20: average income of a poor person has remained virtually unchanged since 2001 at Rwf150 per day against Rwf146 per day in 2001.

9.3. Remaining questions

1. The number of trips to health facilities varies considerably with the availability of DOT services. Community DOT hardly requires travel and food expenditures, whereas health facility DOT does. DOT three times weekly requires less trips than daily intake. The number of trips will also vary depending on length and nature of pre-treatment delays, the practiced procedure, opening hours of diagnostic and treatment facilities and the distance from facility to home of the patient. Delay times are periods in which the patient's productivity is already reduced and indirect costs are incurred. It is difficult to generalize the amount of reduction in productivity across all patients. Another question is whether coping costs can or should be included. It would be easy to calculate additional costs due to debt and interest payments, but it is much more difficult to estimate income loss due to sale of assets or children dropping out of school.

2. We have to assume that not all patients will be able to resume their occupation after the end of treatment and not all patients will complete their treatment. Some will have lost their job, some will have defaulted, some will not be cured. Especially HIV infected TB patients are affected by higher morbidity, less productivity and are therefore subject to continuing indirect costs.

3. None of the studies consulted accounted for a learning curve within a family or community. That is, once a family or community member has undertaken the odyssey from healer to private practitioner to public health facility and has learned about the disease and its symptoms, opening hours of facilities, costs, DOT and – most importantly – cure as treatment result, he/she will share this knowledge with his/her family and community and will be of assistance should another family or community member show TB symptoms. The direct and indirect costs for the second and following patients should therefore be lower than to the first patient.

4. Most tools which were identified during the literature review and which strive for similar aims were survey/questionnaire/interview-based. None of the tools employed (also outside the TB domain) aim to estimate costs without running surveys or operational research projects. This tool should be flexible enough to deliver meaningful data with small sample sizes, not to require too much time to complete and to be adjustable to the national or local context.

5. What about those who don't come at all because of the economic burden of seeking treatment? How could they be reached?

Annex I: List of Reviewed Literature

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